



American Health Care Association



National Center For Assisted Living



American Association  
of Homes and Services  
for the Aging

Voice Of the Retarded

## Joint Statement WORKING TO ENSURE THAT THE PROMISE IS DELIVERED

### Introduction

This statement has been prepared by organizations committed to people who are aging and people with disabilities. We have joined together to lend our informed voices to the development of a national long term care strategy that advances the spirit of the U.S. Supreme Court *Olmstead v. L.C.* decision and provides quality, accessible supports and services to people with disabilities. Together we represent consumer, family and provider organizations.

The need for the development of a national, comprehensive strategy that focuses on people with disabilities in the United States is clear. "Disability," as defined by the Americans with Disabilities Act (ADA), is the presence of one or more physical or mental impairments that limits a major life activity. This definition encompasses individuals of all ages who have cognitive, mental or physical disabilities that result in different types and levels of impairments and include, for example, mental illness, brain injury, autism, mild to profound mental retardation, cerebral palsy, dementia and spinal cord injuries. Long term supports and services must reflect this broad range of disabilities, be designed to meet the needs of the individual, promote choice and inclusion, and be flexible enough to accommodate the changing needs of the individual over time.

A responsible and reasonable national strategy should reflect a heterogeneous population whose needs change over time and should include access to appropriate medical and technological advancements and services and supports in a full range of settings.

The 1999 U.S. Supreme Court's decision in *Olmstead v. L.C.* 19 S.Ct. 2188 (1999) prohibits states from placing persons with disabilities in inappropriate institutional placements, asserting that, under the ADA, continued unjustified institutionalization is a violation of an individual's right to live in the most integrated setting appropriate to his/her needs and to have choices. The Court affirmed each state's obligation to prevent this kind of discrimination. The decision provides a legal framework for efforts to enable individuals with disabilities to receive services in the community. We believe that this obligates the federal government and each state government to adequately fund home- and community-based services (HCBS), which are currently and historically underfunded.



States are required to provide community-based treatment for persons with disabilities when "the State's treatment professionals have determined that such placement is appropriate, the transfer from institutional care to a less restrictive setting is not opposed by the affected individual, and the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities." (Id. at 2185) This statement does not prohibit private treatment professionals, e.g., an interdisciplinary team, from making assessments regarding placement. *Olmstead* also recognizes that "nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings. . . Nor is there any federal requirement that community-based treatment be imposed on patients who do not desire it." *Olmstead v. L.C.* (See also Id. at 2189 (plurality)). Consequently, facility-based services and supports also must be available and adequately funded to enable people with disabilities to receive quality services and supports in all settings.

Spurred by the U.S. Supreme Court ruling in *Olmstead*, federal and each state government and private entities are stepping up efforts to demonstrate implementation of this decision by providing HCBS to persons with disabilities. We are committed to ensuring that the requirements placed upon states as spelled out in the *Olmstead* decision be implemented wisely and that adequate funding be provided for the range of home-and community-based and facility services appropriate to individuals' needs. However, this is a complicated and difficult task given the following factors:

- Chronic underfunding of long-term services and supports;
- The wide range of regulations that vary by state and locality and that often conflict with a commitment to person-centered supports and services;
- The increased need for services as the population ages; and
- A workforce crisis that threatens the quality of supports and services for people with disabilities.

### **Need for Services and Supports**

Estimates of the number of people who require long term services and supports vary. According to a recent General Accounting Office (GAO) report, the total number of people with disabilities in various types of facilities is at least 1.8 million, including 1.6 million elder and persons with disabilities in nursing facilities, 106,000 in facilities for persons with mental retardation and developmental disabilities, and 57,000 in state and county facilities for persons with mental illness. In addition, the GAO states that the number of people living in the community who are at risk of institutionalization is difficult to establish, but estimates that more than 2.3 million people in the community require help from another person to perform two or more self-care activities.

Unpublished data from the National Health Interview Survey on Disability (1994-5), estimates that there are over 12 million people of all ages who need services and supports, which is defined as needing help from another person with one or more activities of daily living (ADLs) and/or instrumental activities of daily living (IADLs). Forty-six (46%) percent of these individuals are under 65, and 3% are between the ages of 5 and 17. Of the total 12 million, 10.2 million individuals (85%) currently reside in the community.



A 2001 George Washington University, School of Public Health and Health Services study based on the ADA's "most integrated setting" complaints to the Department of Health and Human Services' Office for Civil Rights illustrates the need for a broad range of services. Preliminary results indicate that the two most requested services in this study were in-home services - personal, home health, and homemaker/chore - and accessible, affordable housing. Other services included transportation, supplies, and durable medical equipment.

### **Principles\***

An effective, national, comprehensive strategy that provides accessible, quality services and supports must incorporate and reaffirm the following basic principles:

**Independence:** Services should promote individual dignity, maximize independence, self-sufficiency and self-determination, and be provided in the least restrictive setting possible.

**Choice:** People should be able to choose from a full range of health, support and social services so they can receive the types of supports and services that meets their individual needs and preferences.

**Role of Families and Caregivers:** The central role families, caregivers and guardians play in planning for and providing long term care should be recognized and supported.

**Access:** People of all ages should have access to long term services and supports.

**Eligibility:** Eligibility for services should be based on functional, social and health needs that take into account cognitive, mental, physical, and behavioral limitations and the need for support, supervision, and/or training.

**Accountability:** Systems for assuring quality should be built into all services and supports programs. These systems should assure quality and value based on outcomes and consumer protections enforced through appropriate government regulation.

**Standards:** The highest standards of professionalism and quality are essential for caregivers and systems. This must be supported by thorough training, appropriate supervision and fair compensation.

**Coordination:** State service systems should coordinate services for people with multiple needs that change over time, providing a seamless spectrum of services and supports.

### **Recommendations**

On December 21, 2001, Secretary of the U.S. Department of Health and Human Services

---

\* Adapted from *Defining Common Ground: Long Term Care Financing Reform in 2001*, Citizens for Long Term Care, February 2001.



Tommy Thompson released "Delivering on the Promise: Preliminary Report of Federal Agencies' Actions to Eliminate Barriers and Promote Community Integration." The following recommendations support the letter and spirit of "Delivering on the Promise: Preliminary Report" and encompass our guiding principles of Independence, Choice, Role of Families and Caregivers, Access, Eligibility, Accountability, Standards and Coordination.

- The U.S. Department of Justice (DOJ) will develop and disseminate (as it has proposed in "Delivering on the Promise: Preliminary Report") three technical assistance documents: (1) "Know Your Rights," a piece for individuals with disabilities currently living in institutions; (2) a similar document targeted for people at risk of institutionalization; and (3) a document designed to assist states in implementing their responsibilities under *Olmstead*. DOJ should involve the undersigned organizations in this endeavor to assure wide and diverse expertise. Relatedly, we also recommend that DOJ prepare a "Know Your Rights" for people with disabilities who are in the community.
- The Department of Health and Human Services (HHS) should establish task forces made up of public and private stakeholders, including people with disabilities and their families/caregivers/guardians, to enhance and speed efforts to implement *Olmstead* and to ensure that consumers and their families/caregivers/guardians are aware of LTC options. The undersigned organizations would be pleased to assist in the establishment of these task forces.
- HHS should develop and coordinate strategies with other government entities to provide families of children with disabilities, working-age adults with disabilities, and older Americans with disabilities: a) meaningful choice to receive long-term services and supports in the most integrated setting appropriate to their needs; b) monitoring of quality based on outcomes; and c) systems that maximize choice and independence.
- The LTC financing system must support choices across the spectrum of care and help maximize personal independence, self-determination, dignity and fulfillment. It should be as flexible as possible to meet different and changing needs of individuals and to assure appropriate consumer choice in settings across the spectrum of care.
- Federal and state government must be committed to the education of people with disabilities and their representatives, families and guardians on the full array of services and supports options and provide clear and understandable explanations of: a) the services and supports to which they are entitled, b) the alternative settings in which they are entitled to receive services and supports, and c) the differences between the available choices and the physical, service and systemic barriers that may be encountered.
- HHS, in coordination with other agencies, states and providers, needs to find ways to enhance training, education, and support of long term service workers. These might include: a) wage pass throughs or other means to increase wages and/or benefits, b) transportation subsidies, c) creating better training programs that include more hours of training, financial incentives for completing courses in continuing education, using the internet and other means to make training more available, and d) providing career ladders.



- HHS and the Department of Labor must work with states, consumer, family and provider groups to develop and implement a national strategy that addresses the recruitment, retention, and training of stable workforce to provide supports and services to persons with disabilities. Paraprofessional and direct support workers are critical to the quality of long term supports and services, and must be valued and adequately trained and compensated. HHS should involve the undersigned to assure wide and diverse expertise.

### Conclusion

The undersigned consumer, family and provider organizations have joined together with the common goal of ensuring that appropriate supports and services are provided in appropriate settings to qualified individuals who are aging and individuals with disabilities. Encouraged by release of "Delivering on the Promise: Preliminary Report," it is our desire to work jointly with federal and state government to help implement the many proposals offered. We urge HHS and the other Federal agencies to implement, along with their own proposals, our parallel recommendations and to take advantage of our expertise and work with us in partnership to develop and implement an adequately funded, comprehensive, national strategy.

American Health Care Association  
1201 L Street, NW  
Washington, DC 20005-4015  
Phone: (202) 842-4444  
Fax: (202) 842-3860

National Center for Assisted Living  
1201 L Street, NW  
Washington, DC 20005-4015  
Phone: (202) 842-4444  
Fax: (202) 842-3860

American Network of Community Options and Resources  
1101 King Street, Suite 380  
Alexandria, VA 22314  
Phone: (703) 535-7850  
Fax: (703) 535-7860

American Association of Homes and Services for the Aging  
2519 Connecticut Avenue, NW  
Washington, DC 20008  
Phone: (202) 508-9499  
Fax: (202) 783-2255

Voice of the Retarded  
5005 Newport Drive, Suite 108  
Rolling Meadows, IL 60008  
Phone: (847) 253-6020  
Fax: (847) 253-6020